

Editorial

Primary care for persons with spinal cord injury — not a novel idea but still under-developed

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Primary care for persons with spinal cord injury (SCI) has long been recognized as an important issue. Over the last two decades, there has not been any consensus on its contents, pathway or delivery model. Despite the lack of attention on this issue, various health care organizations and settings have successfully developed their own version of primary care for persons with SCI. On the other hand, persons with SCI have also found different ways to obtain primary care through Family Physicians and specialists, often depending on the health care structure of their country. This has blurred the line between what is traditionally seen as primary vs. specialist care. The "medical home" model may be ideal for SCI primary care, and it may be established in different care settings. In order to create this model, health care funding structure, appropriate access to physical facility and SCI knowledge, interdisciplinary provider availability and collaboration, as well as active engagement with persons with SCI are necessary. The SCI community should endorse SCI primary care with effective advocacy and implementation.

In this issue of *The Journal of Spinal Cord Medicine*, Milligan and his team described a progressive effort to enhance primary care for persons with spinal cord injury (SCI).¹ The article describes the process of establishing this successful, inter-professional effort, in their Family Medicine-based clinic in Ontario, Canada which has been funded by provincial funding agencies. Persons with SCI have been actively engaged in the design of this clinic, and there is access to Physiatrists in Spinal Cord Medicine through electronic consultation. This is an important article that has significant implications for the care of persons with SCI, despite the fact that primary care may not have been a focus area in Spinal Cord Medicine. So how is primary care defined? According to the World Health Organization,² primary care is defined as follows:

“...more than just the level of care or gate keeping; it is a key process in the health system. It is first-contact, accessible, continued, comprehensive and coordinated care. First-contact care is accessible at the time of need; ongoing care focuses on the long-term health of a person rather than the short duration of the disease; comprehensive care is a

range of services appropriate to the common problems in the respective population and coordination is the role by which primary care acts to coordinate other specialists that the patient may need.”

A different, but consistent definition of primary care by the Institute of Medicine (U.S.)³ states that it is “the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community.”

Regardless of its precise definition, the philosophy of primary care is one that many providers of Spinal Cord Medicine adopt and utilize on various levels in their daily practice, both in the facility and community settings. Spinal Cord Medicine providers may include, but are not limited to Physiatrists, Neurologists, Internal Medicine physicians, Family Physicians, Nurse Practitioners and Physician Assistants. Even though some of these are specialists who may not be conventionally considered primary care providers, they are often the first point of contact for persons with SCI for health issues, and they play a critical role in the organization and coordination of health care for this population throughout their lifetime. This is

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because Spinal Cord Medicine is unique in that our patients may have special, longitudinal physical and psychosocial needs that cross the boundaries between primary and specialty care in the traditional medicine model, and they often form a lifelong, relationship-based care partnership with their providers, regardless of their practice setting. Ideally, the “medical home”⁴ model should be used for persons with SCI to receive their primary care. So where should this “SCI medical home” be? Whereas many community-based, primary care providers lack SCI expertise and interdisciplinary team support, facility-based Spinal Cord Medicine specialists may lack primary care skills and availability. Yet, persons with SCI may consider different providers in various care settings to be their primary care providers in their “medical homes” for their complex care, blurring the boundaries between the role of the traditional primary care providers and specialists. While this flexibility and fluidity is important for patient-centered care, it may potentially cause confusion in the traditional health care system structure, contributing to the various reasons for the lack of an organized pathway for primary care for persons with SCI.

As early as 1997, Bockenek⁵ described primary care as a fragmented model of care for persons with SCI, advocating for Physiatrists, who are often the primary specialists for persons with SCI, to take on the primary care role. Over the last two decades, there is still discussion as to what primary care for persons with SCI would look like, who would provide the services, and how they would be delivered. To date, there is still not any clear pathway for primary care to be delivered to persons with SCI, nor is there any clinical practice guideline or a significant amount of research in this important area of care.

In fact, a literature search on “spinal cord injury” and “primary care” does not generate too many articles on this topic, while there appears to be much more published literature on the acute management and rehabilitation of persons with SCI. Indeed, the care of persons with SCI appears to have focused more on the acute management and rehabilitation aspects of SCI care, while the primary care and wellness issues seem to have taken a back seat, despite the fact that persons with SCI spend many more years of their lives in the community, where primary care typically takes a more important role, than in the acute hospital and rehabilitation settings. Not surprisingly, many of the reviews and publications on primary care and SCI have come from countries where primary care is an integral part of the health care system, such as European countries, Australia and Canada.⁶ Still, there is no consensus on this topic.

Though there is some evidence that certain aspects of preventive health care, which is an important element of primary care, is obtained by persons with SCI at about the same rate as those without SCI,⁷ larger scale studies have shown that primary care needs are generally not met in persons with SCI, even in countries where primary care is well-established.⁸ Therefore, it is necessary to understand what unique features of primary care are needed for persons with SCI, and the barriers in obtaining them. It has been suggested by a group of Canadian and Australian researchers and clinicians with a special interest in SCI primary care that optimal primary care for persons with SCI would include the following⁹:

- Routine annual comprehensive health evaluation
- Multidisciplinary follow-up to address issues that accompany long-term disability
- Accessible premises that permit full examination of presenting health complaints
- Access to disability-specific expertise in the form of specialists, regarding common secondary complications such as pain, bowel and bladder complications
- Awareness of areas in which there are unmet needs, such as psychological concerns, sexual and reproductive health, and lifestyle issues

It is clear that primary care access for persons with SCI is not only about physical access, but it is also about coordinating and accessing the appropriate and unique skills and knowledge that pertains to Spinal Cord Medicine, as well as the primary care providers understanding the special needs of persons with SCI. In fact, targeted resources and tools do exist to enhance evidence-based SCI knowledge among primary care providers who may not be specialists in Spinal Cord Medicine, such as Family Physicians.^{10,11}

It would be simplistic though, to assume that primary care access to persons with SCI will occur in the community once barriers in physical and knowledge access have been resolved. One must consider it in the broader context of the health care system, as issues such as different funding models and consumer expectations will drive different practices. Comparisons between primary care utilization and access by persons in SCI in western countries (Canada, UK, USA) with different health care delivery models have shown that persons with SCI seek out primary care in different ways, with those in Canada and the UK most likely to seek primary care through Family Physicians, while those in the United States tend to receive care from specialists.¹² It is not clear as to how the long-term outcomes compare between these systems, given such different models of SCI primary care delivery. Interestingly, the sample within the United States was obtained from a

private medical system for SCI care, while in the same country, the United States Department of Veterans Affairs' Spinal Cord Injuries and Disorders (SCI/D) System of Care offers a vastly different model of care for persons with SCI that deserves recognition and discussion, especially in the context of primary care for persons with SCI.

The United States Department of Veterans Affairs' SCI/D System of Care consists of a national network of 24 SCI/D centers and many more locally based clinics that operate on a hub and spokes model of care, providing comprehensive and life-long care that integrates both primary and specialty care within the same network, acting as the medical home for persons with SCI.¹³ Primary care is often delivered at the local clinics (the “spokes” sites) while SCI primary and specialty care is delivered at the SCI/D centers (the “hubs”). For instance, SCI annual comprehensive health evaluations are routinely performed at the “spokes” sites, whereas preventive care such as colonoscopy is a coordinated effort between the “spokes” and the “hub” sites, as the presence of neurogenic bowel often makes it too complicated and involved for effective bowel preparation to be performed in the community setting, necessitating admission to the “hub” sites. Despite being a very successful model for SCI care, there is little research on its long-term outcomes, when compared with the private system for SCI care in the United States. Intuitively though, this comprehensive system of care would seem to be the ideal model for longitudinal primary and specialty care for persons with SCI.

In order for primary care for SCI to be fully recognized and widely implemented in a standardized fashion, it needs to be completely embraced by the SCI community, with the necessary advocacy for these key issues at all levels in the health care system:

- Health care funding model needs to be appropriate for providers to deliver the complex primary care that persons with SCI need – this includes appropriate funding for clinician training and reimbursement, physical access, and interdisciplinary team structure to create the SCI “medical home”;
- Development of interdisciplinary SCI primary care special interest groups, leading to standardized SCI primary care guidelines, outlining the necessary goals and requirements for such care to be delivered flexibly – it may be in the community or in the facility settings, or a combination, depending on the local health care system resources and needs, as well as consumer preferences;
- Effective outreach and collaboration between the community-based providers and facility-based specialists, combining the expertise of both to deliver the right care at the right place and the right time;
- Active engagement of persons with SCI in the design of SCI primary care;
- Research and quality improvement effort to ensure measurable outcomes will be studied in order to help to refine the SCI primary care design.

Suffice it to say that primary care for persons with SCI is indeed not a new concept. Most if not all, clinicians will agree on its importance. Milligan's community clinic and the examples above have shown us that even in the absence of overall consensus and standardization on its contents and delivery methods, primary care can be, and is already delivered successfully in different settings, with varying levels of system support and endorsement. Given all of the benefits and importance of having a robust system of primary care for persons with SCI, the SCI community should whole-heartedly endorse this with effective advocacy and implementation, creating the “SCI medical home”.

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